Jacek Nasiłowski[1], Zbigniew Szkulmowski[2], Marek Migdał[3], Witalij Andrzejewski[4], Wojciech Drozd[5], Małgorzata Czajkowska-Malinowska[6], Andrzej Opuchlik[7], Ryszarda Chazan[1]

[1]Department of Internal Medicine, Pneumonology and Allergology, Medical University of Warsaw, Poland
Head: Prof. R. Chazan, M.D., Ph.D.
[2]Medycyna Specjalistyczna Sp. z o.o., Bydgoszcz, Poland
Practice Manager: Z. Szkulmowski, M.D., Ph.D.
[3]Department of Anaesthesia and Intensive Care, The Children's Memorial Health Institute, Warsaw, Poland
Head: M. Manowska, M.D., Ph.D.
[4]Łódź Hospice for Children and Adults, Łódź, Poland
Director: J. Adamczyk, MSc
[5]NZOZ BETA-MED, Katowice, Poland
Practice Manager: B. Drzazga, MSc
[6]Department of Lung Diseases and Respiratory Failure, Kujawsko-Pomorskie Pulmonology Centre, Bydgoszcz, Poland
Head: M. Czajkowska-Malinowska, M.D., Ph.D.
[7]Department of Neurology, Medical University of Warsaw, Poland
Head: Prof. H. Kwieciński, M.D., Ph.D.

Prevalence of home mechanical ventilation in Poland

Abstract

Introduction: Home mechanical ventilation (HMV) is increasingly used in the treatment of chronic respiratory failure further to rapid technological development, increasing number of elderly people and extension of indications. The aim of the study was to assess: prevalence of HMV in Poland, the proportions of lung disease and neuromuscular patients using HMV and the type of interface (invasive *v.* non-invasive).

Material and methods: The questionnaire was sent to all institutions providing HMV in Poland and to regional departments of National Health System (NHS).

Results: All NHS departments responded. They reported 846 HMV users, 31% of whom were children. The prevalence of HMV in Poland was assessed as 2,2 patient per 100.000 population without striking differences between provinces. Among 39 HMV centers in Poland 12 (31%) answered. They reported 206 patients (24% of all HMV users). Proportion of ventilation mode consisted of 59% (122 pts) treated via a tracheostomy and 41% (84 pts) with non invasive ventilation (NIV). 168 patients (82%) had neuromuscular diseases (ND), majority of them muscular dystrophy — 57 patients (34% of ND) and amyotrophic lateral sclerosis — 39 patients (23% of ND). There were only 38 patients (18%) with lung and thoracic cage diseases: 17 with COPD and 10 with kyphoscoliosis.

Conclusions: The prevalence of HMV treatment in Poland has developed dramatically in the last decade, but is still very low comparing to other European countries, especially due to very low number of patients with lung and chest wall diseases. The prevalence of invasive mode of ventilation is extremely high. The most important factors which inhibit development of HMV in Poland are: omission of respiratory physicians in the process of qualification, lack of national guidelines, sophisticated demands for HMV providers. The awareness of the need of HMV especially in patients with respiratory failure due to obesity hypoventilation syndrome and restrictive lung diseases should be increased among chest physicians.

Key words: home mechanical ventilation, prevalence, non-invasive ventilation, chronic respiratory failure

Pneumonol. Alergol. Pol. 2010; 78, 6: 392–398

Corresponding author: Jacek Nasiłowski M.D., Department of Internal Medicine, Pneumonology and Allergology, Medical University of Warsaw, Banacha St. 1a, 02–097 Warszawa, Poland, tel.: +48 22 599 2851, fax: +48 22 599 1560, mobile: +48 606 837 025, e-mail: jnasilowski@wum.edu.pl

Received:10 May 2009

ISSN 0867–7077

Introduction

Although mechanical ventilatory support was first introduced in the nineteenth century [1], it was not until the second half of the twentieth century that progress in this method of treatment gained real momentum. In the first half of the twentieth century mechanical ventilation was carried out by generating a negative pressure around the chest. In 1948, when a piston ventilator was first designed, the supply of air under a positive pressure into the airways became the basic method for artificial ventilation [2], with chronic ventilation being carried out through a tracheostomy. The 1990s saw rapid development of non-invasive techniques involving the use of masks, associated with the treatment of obstructive sleep apnoea [3]. Being considered more patient-friendly, this method is currently used long-term by many patients, replacing — in most cases — ventilation carried out by invasive methods.

Mechanical ventilatory support is becoming an increasingly popular method of long-term treatment in patients with chronic respiratory failure. Because of technological progress, we can now enjoy more and more modern, doctor- and patient-friendly ventilators. There is also constant progress as regards the masks for non-invasive ventilation, which improves the tolerability and efficacy of this form of treatment.

An analysis of home ventilation in 16 European countries performed in 2001–2002, known as the Eurovent study, showed that the prevalence of this method of treatment is 6.6 per 100,000 inhabitants, with considerable country-to-country variations: from 0.6 per 100,000 in Greece to 17 per 100,000 in France [4]. This study also provided data on Poland. At that time only 40 patients from all over Poland were reported, which gave the lowest European average of only 0.1 per 100,000.

In Poland, ventilation support in the home setting is subject to reimbursement by the National Health Fund and is offered by specialised centres, namely home care teams, which are often part of home hospices that provide the patients with the necessary equipment, medical and nursing care, and rehabilitation services under a contract with the National Health Fund [5].

In the past decade or two there has been constant progress in the organisation of home healthcare in Poland. New home hospices have been opened and the existing ones have considerably expanded the scope of their services [6]. There has been an increase in the awareness of the humanitarian and economic need for transferring care for the chronically ill from hospital to the home settings. There has also been an expansion of indications for long-term ventilation. Home mechanical ventilation (HMV) is now being offered to patients with COPD and obesity hypoventilation syndrome in addition to patients with neuromuscular diseases, post-injury spinal changes, and chest wall deformities, who were the initial beneficiaries of this method of treatment [7].

Another factor affecting the development of HMV in Poland is the increasing access to the ventilators and equipment necessary to carry out artificial ventilation. Also, the progress in intensive care, particularly in the treatment of children, has significantly increased the number of patients on long-term ventilation.

Taking into account the above factors that stimulate the development of mechanical ventilation in the home setting, we decided to estimate the current prevalence of this method of treatment, the profile of indications, and the methods of HMV.

Material and methods

In order to gather information on HMV in Poland the initial step involved sending out surveys to centres that had signed a contract with the National Health Fund to conduct this form of therapy. The survey contained questions about the year in which the centre was established, the number of patients currently treated, and questions about patient characteristics in terms of the cause of respiratory failure and the interface type: invasive vs. non-invasive. If a centre failed to respond by mail, it was contacted by telephone. All the returned surveys were completed by doctors responsible for the co-ordination of HMV at the centres.

The second step involved sending out surveys by e-mail to all the National Health Fund provincial branch offices. The surveys asked for information on the following:

— the number of patients currently receiving HMV in a given province, specifying the number of children and the number of adults;
— the number of centres currently providing HMV in a given province;
— ICD-10 codes which were reported as an indication for HMV.

Written requests were sent to any National Health Fund provincial branch offices that required it. Due to the ambiguity of ICD-10 codes reported by the National Health Fund provincial branch offices, they were not used for the analysis of indication profiles. The most commonly reported codes (235 cases) were: J96 (respiratory failure,

not classified elsewhere) and J96.1 (chronic respiratory failure). These codes do not point to any specific disease that would constitute an indication for HMV. We therefore performed the analysis using information reported in the surveys completed by doctors from centres providing HMV.

In order to calculate the mean number of patients treated with HMV per 100,000 inhabitants, we used demographic data published by the Polish Central Statistical Office [8].

Results

Between August and December 2008 we received completed surveys from 12 centres (31% of all the registered centres providing HMV in Poland). Between December 2008 and June 2009 we received responses from all National Health Fund provincial branch offices regarding the number of HMV users, including information from 14 provincial branch offices specifying the number of children and the number of adults. All the provincial branch offices but one specified the number of centres providing HMV in a given province.

At the end of 2008 and in the beginning of 2009 there were 846 HMV users in Poland, or an average 2.2 users per 100,000 inhabitants. The prevalence of HMV was highest in the Lubelskie province (4 per 100,000) and lowest in the West Pomeranian province (1.18 per 100,000). Based on the data from 14 provinces (except for the Łódzkie and Mazovian provinces) the proportion of children among HMV users can be estimated at 31%. More details on the prevalence rates and the numbers of patients by province are provided in Figure 1 and Table 1.

Thirt-nine centres were providing HMV. The mean number of centres per province was 4.4 (range 1–12).

The 12 centres which responded to the survey reported a total of 206 patients (24% of all HMV users in Poland under the National Health Fund procedure) or an average of 17 users per centre (range 1–50). Four centres were established before 2000 and 8 after 2000.

Out of the 206 reported users, 122 (59%) were receiving HMV via a tracheostomy and 84 (41%) by non-invasive means: using facial or nasal masks. The most common reason for using HMV was neuromuscular disease (168 [82%] patients) with the remaining reasons being lung and thoracic cage disease (38 [18%] patients). The most common diagnoses in the patients with neuromuscular diseases were: amyotrophic lateral sclerosis (39 [23%] patients) and spinal muscular atrophy (25 [15%]).

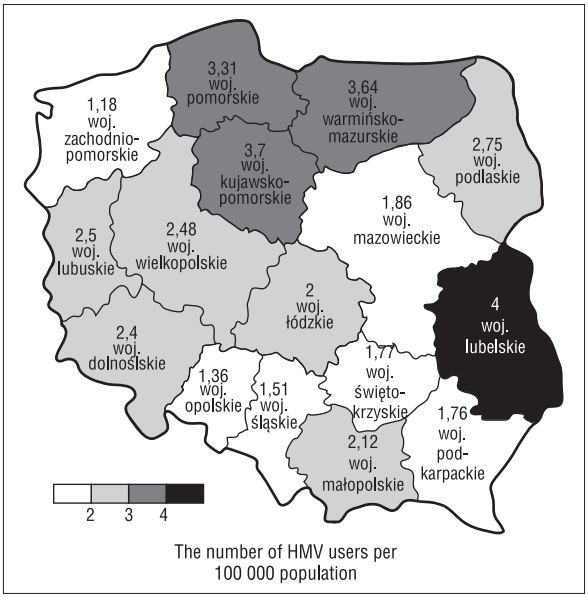

Figure 1. Prevalence of home mechanical ventilation in provinces of Poland. The numbers mean number of patients treated with HMV per 100,000 of the population

The most common indications for HMV among patients with respiratory diseases were COPD (17, 45% patients with lung and thoracic cage diseases) and kyphoscoliosis (10 [26%] patients). Less frequent causes included: interstitial lung disease (4 patients) and obesity hypoventilation syndrome (3 patients). Table 2 provides the list of indications for HMV.

Discussion

The total number of patients using HMV in Poland who were financed by National Health Fund is 846 or an average of 2.2 patients per 100,000 inhabitants. This means that in the past decade there has been considerable progress in the use of HMV in Poland. The number of patients using this method of treatment has risen 20-fold compared to the number reported by the Eurovent study covering the period from 2001 to 2002, when only 40 patients receiving long-term mechanical ventilation were reported in Poland [4]. Despite the rapid development of the method in Poland, its prevalence is still very low compared to Western European countries, where it averages 16 patients per 100,000 inhabitants [9].

The prevalence of HMV in individual Polish provinces is quite uniform and is not region-dependent.

Data from 12 centres which completed the survey represents merely a quarter of all the HMV users in Poland. However, taking into account the

Table 1. Prevalence of home mechanical ventilation in Poland depending on province

Province	Population	Number of patients	Prevalence per 100 000 of the population	Number of centers	Children	Adults
Lubelskie	2 187 918	88	4	3	76	12
Kujawsko-pomorskie	2 067 548	78	3.7	3	19	59
Warmińsko-mazurskie	1 428 385	51	3.64	3	10	41
Pomorskie	2 192 404	73	3.31	6	14	59
Podlaskie	1 204 036	33	2.75	5	12	21
Lubuskie	1 009 177	25	2.5	4	7	18
Wielkopolskie	3 362 011	82	2.48	5	32	50
Dolnośląskie	2 895 729	71	2.4	4	14	57
Małopolskie	3 256 171	70	2.12	4	9	61
Łódzkie	2 592 568	52	2	4	NA	NA
Świętokrzyskie	1 290 176	25	1.92	NA	3	22
Mazowieckie	5 139 545	95	1.86	6	NA	NA
Podkarpackie	2 097 325	37	1.76	1	7	30
Śląskie	4 707 825	31	1.51	12	5	26
Opolskie	1 053 723	15	1.36	3	5	10
Zachodnio-Pomorskie	1 695 708	20	1.18	3	3	17
Poland	38 180 249	846	**2.21**	**39**	**216**	**483**

NA — not available

random distribution of these centres, the results provided by them may be treated as roughly representative for Poland. According to these results, more than half of the patients are ventilated invasively via a tracheostomy, which largely departs from the methods of HMV in Western Europe, where invasive ventilation is rarely used.

The Eurovent study showed that only 13% of patients are ventilated via a tracheostomy [4]. Currently the prevalence of invasive mechanical ventilation in Europe is estimated at 5% [9, 10]. In Poland a large neumber of patients ventilated invasively results most likely from the predominance of patients with neuromuscular diseases, who account for more than 80% of all the HMV users. However, even in this group of patients, invasive ventilation is used less frequently in other countries (in a total of 24% of users in the Eurovent study or in 40% of users in northern Italy) [9].

Patients with respiratory diseases accounted for one-fifth of HMV users in Poland, compared to over 2/3 in the Eurovent study [4]. According to the registries of HMV users in Sweden or Switzerland, on the other hand, the percentage of patients with lung and thoracic cage diseases using HMV is about 80% [10, 11].

The prevalence of HMV among COPD patients is increasing [10] despite there not being any unequivocal scientific evidence supporting its efficacy. Also, in Poland, patients with COPD are the most numerous group of patients within the lung and thoracic cage disease category. An Italian randomised study published in 2002 comparing the efficacy of HMV versus long-therm oxygen therapy (LTOT) in chronically hypercapnic patients with COPD failed to show improved survival over 2 years of follow-up. An improvement in the quality of life was, however, observed, as measured by the specific questionnaire for patients with severe respiratory failure [12]. A more recent study by McEvoy et al. showed modest, but statistically significant improvement in prognosis at the expense of a deterioration in quality of life. The questionnaires used in the study were not, however, specific for patients with respiratory failure [13].

The benefits of HMV in patients with lung and thoracic cage diseases with a restrictive pattern are so unquestionable that no randomised studies have ever been conducted in this patient group, such studies being considered unethical. Evidence supporting the beneficial effects of long-term ventilation on the prognosis may, therefore, be gained

Table 2. Indications for home mechanical ventilation, data from 12 center

Condition of respiratory failure	Invasive ventilation via tracheostomy	*Non-invasive ventilation*
Muscular dystrophy	28	29
Motor neuron disease	26	13
Spinal muscular atrophy	17	8
Brainstem celebrovascular accident	11	–
Myopathie	6	–
Congenital central hypoventilation syndrome	4	–
Cervical spinal cord lesion	3	2
Other neuromuscular and metabolic diseases	18	3
COPD	3	14
Kyphoscoliosis	3	7
Lung fibrosis	2	2
Obesity hypoventilation syndrome	–	3
Other lung and chest wall diseases	1	3
Total	**122**	**84**

from observational studies. Jäger et al. published results of a study in which they followed up patients with complete respiratory failure due to post-tuberculosis lung disease. In the group of HMV patients the mortality risk was 3 times lower than in the group of patients on LTOT only [14]. Identical results in a multivariate analysis (a 3-fold reduction in mortality risk) were obtained by Gustafson et al. in a similar study in patients with idiopathic kyphoscoliosis [15]. Given such evident benefits of using HMV in restrictive diseases, the small number of patients with these types of conditions managed by HMV in Poland are alarming. The centres which completed the survey reported a total of only 10 patients managed for kyphoscoliosis and not one patient with complete respiratory failure due to tuberculosis sequelae.

Obesity hypoventilation syndrome (OHS) is currently the most common reason for using HMV [10]. OHS is defined as obesity (BMI > 30 kg/m^2) and persistent hypercapnia ($PaCO_2$ > 45 mm Hg) in the absence of other causes of hypoventilation [16]. When left without treatment with mechanical ventilation, patients with OHS develop pulmonary hypertension, are at risk of recurrent exacerbations of hypercapnic respiratory failure, and are at an increased risk of exacerbation and death [17]. In our study, only 3 patients with this disorder were reported in the survey. We believe that in most of cases the diagnosis in these patients is limited to obstructive sleep apnoea (OSA), which coexists with OHS in the majority of patients. The patients most commonly receive treatment with CPAP, which is often effective. However, a study by Banerjee et al. showed that 43% of patients with co-existent OSA and OHS had reduced oxygen saturation below 90% for more than 20% of sleep time despite effective treatment of upper airway obstruction with CPAP [18]. Such patients, as well as patients with OHS without OSA, require ventilatory support and oxygen supplementation.

The low number of patients with restrictive diseases of the respiratory tract and OHS may result from the current principles of qualification for HMV. The only doctor authorised to qualify a patient for HMV is a specialist in anaesthesia and intensive care [19, 20]. A pulmonologist, who normally looks after such patients, even if experienced in the treatment with ventilatory support, is not authorised to initiate such therapy. The situation is further complicated by the lack of clear criteria established by scientific societies that would facilitate the decision to initiate such treatment. Exceptions to this are recommendations on the principles of qualification and treatment of children in HMV programmes, which have been published twice by Migdał et al. [21, 22].

Other factors that hamper the development of HMV are the extremely strict requirements for providing this service imposed by the National Health Fund. A centre offering HMV is obliged to provide each patient with a ventilator fitted with an internal battery that lasts for 4 hours, whether the patient requires constant or only temporary ventilation - which is most often the case with patients suffering from lung and thoracic cage diseases. In

addition, the National Health Fund obliges the doctor to visit each patient once a week with each visit lasting 1.5 hours. It also requires two visits of a nurse specialised in anaesthesia, also 1.5 hours each, and two visits of a rehabilitation technician [23]. Such comprehensive and frequent monitoring of HMV user is unique in the European scale and requires revision.

In France, the European leader in HMV, the patient is visited at home every three months by a technician appropriately trained to operate HMV equipment. Contact with the pulmonologist takes place during regular clinic visits [24]. A similar scenario of home visits exists in the United Kingdom [25].

The increase in the number of HMV users in Poland is a positive phenomenon and reflects the improvement of the healthcare system that has occurred in the past decade. First of all, there has been an increase in the awareness of this option among doctors. Access to the equipment has become easier thanks to the wider offer on the market and the lower purchasing costs. There has also been a significant increase in the reimbursement of treatment costs by the NHS. Despite this evident improvement, one should bear in mind the considerable gap between Poland and Western European countries. This gap means that many patients in Poland are not offered appropriate treatment. This mainly applies to patients with lung and thoracic cage diseases and patients with OHS. Very high percentage of patients on invasive ventilation suggests late qualification and insufficient awareness of non-invasive ventilation options on the part of chest medicine specialists.

Our study is one of the first publications in the Polish literature to present the issue of HMV in Poland. One of the weaknesses of our study is a low response rate provided by the HMV centres. Only 31% of the centres responded to our survey, reporting data on 24% of patients treated using this method. Most centres are non-public healthcare establishments, which are not interested in sharing information for scientific purposes. Despite this, it seems that our results reflect the actual status of HMV in Poland quite reliably.

Conclusions

The system of qualification for HMV requires some changes. First of all, it is necessary to authorise pulmonologists experienced in the treatment of patients with chronic respiratory failure to carry out the qualification process for HMV. Scientific societies should develop appropriate guidelines related to qualification criteria, as is the case with home oxygen therapy. In addition, the principles of care (e.g. the frequency of home visits) and equipment requirements should be adapted to the actual patient's needs.

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